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## **Physician and Surrogate Agreement with Assisted Dying and Continuous Deep Sedation in Advanced Dementia in Switzerland**

Loizeau, Andrea Jutta ; Cohen, Simon M ; Mitchell, Susan L ; Theill, Nathan ; Eicher, Stefanie ;  
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**Abstract:** Background: Assisted dying and continuous deep sedation (CDS) are controversial practices. Little is known about the perceptions of physicians and surrogates about these practices for patients with advanced dementia. Objectives: To describe and compare physician and surrogate agreement with the use of assisted dying and CDS in advanced dementia. Design, Setting, Subjects: Physicians (n = 64) and surrogates (n = 168) of persons with advanced dementia were recruited as part of a randomized controlled trial in Switzerland that tested decision support tools in this population. Methods: At baseline, the participants were asked about their agreement with assisted dying and CDS in advanced dementia using the following response options: “completely agree,” “somewhat agree,” “somewhat disagree,” “completely disagree,” and “do not know.” Multivariable logistic regressions compared the likelihood that surrogates versus physicians would completely or somewhat agree (vs. completely or somewhat disagree) with these practices. Results: The physicians and surrogates, respectively, had a mean age (SD) of 50.6 years (9.9) and 57.4 years (14.6); 46.9% (n = 30/64) and 68.9% (n = 115/167) were women. A total of 20.3% (n = 13/64) of the physicians and 47.0% (n = 79/168) of the surrogates agreed with assisted dying in advanced dementia. Surrogates were significantly more likely to agree with this practice than physicians (adjusted odds ratio, 3.87; 95% CI: 1.94, 7.69). With regard to CDS, 51.6% (n = 33/64) of the physicians and 41.9% (n = 70/169) of the surrogates agreed with this practice, which did not differ significantly between the groups. Conclusions: The surrogates were more agreeable to considering assisted dying in the setting of advanced dementia than the physicians, and about half of the participants in both groups reported CDS to be an appropriate option for this population.

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# Physician and Surrogate Agreement with Assisted Dying and Continuous Deep Sedation in Advanced Dementia in Switzerland

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## Keywords

Dementia · Assisted dying · Sedation · End of life ·  
Decision-making

## Abstract

**Background:** Assisted dying and continuous deep sedation (CDS) are controversial practices. Little is known about the perceptions of physicians and surrogates about these practices for patients with advanced dementia. **Objectives:** To describe and compare physician and surrogate agreement with the use of assisted dying and CDS in advanced dementia. **Design, Setting, Subjects:** Physicians ( $n = 64$ ) and surrogates ( $n = 168$ ) of persons with advanced dementia were recruited as part of a randomized controlled trial in Switzerland that tested decision support tools in this population. **Methods:** At baseline, the participants were asked about their agreement with assisted dying and CDS in advanced dementia using the following response options: "completely agree," "somewhat agree," "somewhat disagree," "com-

pletely disagree," and "do not know." Multivariable logistic regressions compared the likelihood that surrogates versus physicians would completely or somewhat agree (vs. completely or somewhat disagree) with these practices. **Results:** The physicians and surrogates, respectively, had a mean age (SD) of 50.6 years (9.9) and 57.4 years (14.6); 46.9% ( $n = 30/64$ ) and 68.9% ( $n = 115/167$ ) were women. A total of 20.3% ( $n = 13/64$ ) of the physicians and 47.0% ( $n = 79/168$ ) of the surrogates agreed with assisted dying in advanced dementia. Surrogates were significantly more likely to agree with this practice than physicians (adjusted odds ratio, 3.87; 95% CI: 1.94, 7.69). With regard to CDS, 51.6% ( $n = 33/64$ ) of the physicians and 41.9% ( $n = 70/169$ ) of the surrogates agreed with this practice, which did not differ significantly between the groups. **Conclusions:** The surrogates were more agreeable to considering assisted dying in the setting of advanced dementia than the physicians, and about half of the participants in both groups reported CDS to be an appropriate option for this population.

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## Introduction

Dementia afflicts more than 50 million people worldwide and is one of the most common causes of death in Switzerland [1, 2]. In advanced dementia, patients have profound cognitive and functional deficits, and they experience clinical complications that may cause discomfort and a poor quality of life [3–5].

Assisted dying is a controversial practice that has been used in certain contexts for patients with life-limiting disease [6]. Assisted dying is when a physician either administers drugs that cause a person to die (i.e., euthanasia) or provides lethal drugs for self-administration (i.e., physician-assisted suicide) [7]. In the case of euthanasia, the physician takes an active role in completing the request of the patient incapable of completing the final act, for instance, by administering a lethal injection. In assisted suicide, the physician solely makes lethal means available to the patient, but the completion of the final act is left to the patient. Currently, physician-assisted dying is legal in only a few states in the USA as well as in a limited number of countries, including Switzerland [6, 8, 9]. However, only the Netherlands, Belgium, and Luxembourg allow assisted dying for people with advanced dementia [10]. This request must be made in an advance directive by a patient with dementia when decision-making capacity is still intact. Only limited research exists on the perceptions of physicians and surrogates about the use of assisted dying in advanced dementia [11–15].

Another controversial practice for terminally ill patients is continuous deep sedation (CDS) until death, a last-resort palliative practice to alleviate suffering [16, 17]. Medications are administered until death to lower the level of consciousness and relieve refractory symptoms of patients with a life expectancy of typically less than 2 weeks [18]. To date, CDS has predominantly been used for advanced cancer patients who are experiencing extreme physical suffering in their final weeks of life [16, 19]. CDS has rarely been used in advanced dementia, a condition predominantly characterized by cognitive impairments, with some, but typically less, physical suffering than metastatic cancer [3, 5, 20].

To better understand the perceptions of physicians and surrogates about the use of assisted dying and CDS in advanced dementia, we analyzed baseline data from a randomized controlled trial, the DEMentia FACT boxes (DEMFACt) Study, conducted in the Swiss German region of Switzerland. The objec-

tives of this report were to (1) describe physician and surrogate agreement with the use of assisted dying and CDS in advanced dementia, and (2) compare the agreement with the use of these practices in these two groups.

## Subjects and Methods

### *Data Source*

The data were retrieved from baseline assessments made in the DEMFACT Study, conducted between June 2016 and October 2016 in the Swiss German region of Switzerland. DEMFACT was a randomized controlled trial that evaluated FACT box decision support tools for treatment decision-making regarding advanced dementia among 64 physicians and 168 surrogates (relatives of dementia patients,  $n = 100$ ; professional guardians,  $n = 68$ ) who were randomized to either an intervention arm ( $n = 114$ ) or a control arm ( $n = 118$ ) [21]. The participants in the intervention and control arms were mailed written questionnaires at baseline and 1 month later that included questions about the use of treatments for advanced dementia patients based on hypothetical scenarios. At the 1-month follow-up, the intervention participants received the decision support tools, whereas the control participants were given no additional information.

The main DEMFACT Study compared changes in prespecified outcomes between the baseline and follow-up assessments in the intervention arm relative to the control arm. In this report, combined data from the baseline questionnaires in both arms (i.e., before receiving the decision support tools in the intervention arm) were analyzed to describe agreement with the use of continuous sedation and assisted dying in advanced dementia. The baseline questionnaires were completed between June 2, 2016, and July 31, 2016.

### *Population*

To understand the impact of the DEMFACT intervention on various decision-makers, the participants included physicians as well as surrogates (relatives of dementia patients and professional guardians) who were potentially responsible for the care of advanced dementia patients. Physicians were identified from the mailing lists of the Swiss Association for Palliative Medicine, Care and Support, and the Swiss Geriatric Medicine Society. Surrogates were identified either through the Alzheimer Association of the canton of Zurich or from the Swiss Association of Professional Guardians mailing list. The detailed recruitment procedure is described elsewhere [21]. Eligible participants were mailed a consent form, which they were asked to sign and return to the research team.

### *Data Elements*

Data collection was procedurally identical across physician and surrogate participants. All variables in this report were collected at the DEMFACT baseline assessment using a written questionnaire sent and returned by mail (approx. 60 min to complete).

**Table 1.** Characteristics of the physicians and surrogates ( $n = 232$ )

Characteristics	Physicians ( $n = 64$ )	Surrogates ( $n = 168$ )
Mean age $\pm$ SD <sup>a</sup> , years	50.6 $\pm$ 9.9	57.4 $\pm$ 14.6
Age >55 years <sup>b</sup>	21 (32.8)	91 (54.5)
Female <sup>a</sup>	30 (46.9)	115 (68.9)
Nationality <sup>a</sup>		
Swiss	44 (72.1)	157 (94.6)
German	13 (21.3)	7 (4.2)
Other	4 (6.6)	2 (1.2)
Religion <sup>a</sup>		
Protestant or catholic	44 (68.8)	108 (65.5)
Other	9 (14.1)	11 (6.7)
No religion	10 (15.6)	38 (23.0)
Refused to answer	1 (1.6)	8 (4.8)
Education <sup>a</sup>		
High school or higher	64 (100)	161 (97.0)
Any prior major treatment decision in dementia <sup>a, c</sup>	58 (90.6)	42 (25.3)

Values denote  $n$  (%) unless specified otherwise. <sup>a</sup> The total number of missing values by characteristic was: age,  $n = 1$ ; female,  $n = 1$ ; nationality,  $n = 5$ ; religion,  $n = 3$ ; education,  $n = 2$ ; and any prior major treatment decision,  $n = 2$ . <sup>b</sup> Median age. <sup>c</sup> Decision-makers reported whether they had or had not previously made any major decision about the use of antibiotics and/or artificial hydration for a person with advanced dementia.

The outcomes were participants' agreement with the use of assisted dying and CDS in advanced dementia. Agreement with assisted dying was ascertained using the following question: "The current legislation prohibits physician-assisted suicide (assisted dying) for persons lacking the capacity to consent. This prevents persons with advanced dementia from accessing the services of assisted dying organizations. Independent of the current legal situation, would you personally support the use of assisted suicide (one form of physician-hastened death) for persons with advanced dementia?" Agreement with the use of CDS was measured as follows: "At the end of life, it is possible to use medications, administered until death, to relieve the symptoms of a person with advanced dementia and put them into a permanent, artificial sleep (continuous sedation). Would you personally support the use of continuous sedation for persons with advanced dementia?" For both questions, the participants were asked to select one of the following response options: "completely agree," "somewhat agree," "somewhat disagree," "completely disagree," or "do not know."

Other participant data assessed at baseline included demographics (age, gender, nationality [Swiss, German, and other], religion [Protestant or Catholic, other religion, no religion, and refused to answer], and educational level [ $\geq$ high school vs. other]) and whether participants had previously decided about the use of antibiotics and/or artificial hydration for a person with advanced dementia.

### Analysis

The analyses were performed using R version 3.3.2 (Boston, MA, USA). Means with standard deviations (SDs) and frequencies describe continuous and categorical variables, respectively.

Logistic regression was used to examine the association between decision-maker type (surrogate vs. physician) and agreement with the following practices in advanced dementia (outcomes): (1) assisted dying and (2) CDS. For each practice, the outcome was dichotomized as "agree" (i.e., "completely agree" and "somewhat agree") versus "disagree" (i.e., "completely disagree" and "somewhat disagree") and excluded "do not know" responses. Covariates considered a priori to be possibly associated with supporting the use of assisted dying or CDS [13] included participants' demographic characteristics (age [dichotomized at the median], gender, and religion [dichotomized as "no religion" vs. "any," excluding "refused to answer"]) and prior decisions about the use of antibiotics and/or artificial hydration in advanced dementia (dichotomized as "any prior major treatment decision" vs. "none"). Bivariable analyses examined the unadjusted associations between each covariate and the outcome. Variables associated with the outcome at  $p < 0.10$  in the unadjusted analyses were entered into a multivariable model. The final adjusted model included those variables significantly associated with the outcome at  $p < 0.05$ . Adjusted odds ratios (AORs) with 95% confidence intervals (CIs) were computed. A sensitivity analysis examined whether the association differed as a function of subgroup (relatives vs. proxies), since perceptions might not have been homogeneous across subgroups.

## Results

### Subject Characteristics

Of the 3,860 individuals approached for participation, 254 (6.6%) contacted the research team indicating their willingness to participate, and all were eligible for enrollment. Prior to study completion, 15 participants (5.9%) stopped responding to e-mails and/or phone calls (physicians,  $n = 9/74$  [12.2%]; surrogates,  $n = 6/180$  [3.3%]) and 7 participants (2.8%) withdrew (physicians,  $n = 1/74$  [1.4%]; surrogates,  $n = 6/180$  [3.3%]). The final sample included the remaining 64 physicians and 168 surrogates.

The baseline characteristics of the physicians and surrogates are shown in Table 1. The physicians' mean age (SD) was 50.6 years (9.9); 46.9% ( $n = 30/64$ ) were women and 72.1% ( $n = 44/61$ ) were Swiss. The surrogates' mean age (SD) was 57.4 years (14.6); 68.9% ( $n = 115/167$ ) were women and 94.6% ( $n = 157/166$ ) were Swiss. A total of 68.8% ( $n = 44/64$ ) of the physicians and 65.5% ( $n = 108/165$ ) of the surrogates reported being either Protestant or Catholic. A total of 90.6% ( $n = 58/64$ ) of the physi-



**Table 2.** Association between decision-maker type and agreement with the use of assisted dying in advanced dementia

	Decision-makers with the characteristic ( <i>n</i> = 218), <i>n</i> (%)	Decision-makers agreeing with assisted dying ( <i>n</i> = 92), <i>n</i> (%)		Odds ratio <sup>a</sup> for agreement with assisted dying (95% CI)	
		characteristic present	characteristic absent	unadjusted	adjusted
<i>Characteristic</i>					
Surrogate (vs. physician)	156 (71.6)	79 (36.2)	13 (6.0)	3.87 (1.94, 7.69) <sup>d</sup>	3.87 (1.94, 7.69)
<i>Covariates</i>					
Age >55 years <sup>b</sup>	106 (48.8)	54 (24.9)	38 (17.5)	1.99 (1.15, 3.45) <sup>d</sup>	
Female <sup>b</sup>	133 (61.3)	62 (28.6)	30 (13.8)	1.57 (0.90, 2.76)	
No religion (vs. any) <sup>b</sup>	45 (21.4)	24 (11.4)	67 (31.9)	1.67 (0.86, 3.24)	
Any prior major treatment decision in dementia <sup>b, c</sup>	97 (44.9)	29 (13.4)	61 (28.2)	0.41 (0.23, 0.71) <sup>d</sup>	

Decision-makers: 42.2% (*n* = 92/218) agreed with the use of assisted dying in advanced dementia. <sup>a</sup> Logistic regression was used in all analyses, and unadjusted and adjusted odds ratios were computed. <sup>b</sup> The total number of missing values was: age, *n* = 1; female, *n* = 1; no religion, *n* = 8 (missing values, *n* = 3; refused, *n* = 5); and any prior major treatment decision, *n* = 2. <sup>c</sup> Decision-makers reported whether they had or had not previously made any major decision about the use of antibiotics and/or artificial hydration for a person with advanced dementia. <sup>d</sup> Variables that were significant at *p* < 0.10 in the bivariable analyses and entered into the multivariable model.

cians had previously made a major treatment decision for a person with advanced dementia, whereas only 25.3% (*n* = 42/166) of the surrogates had ever made such a decision.

#### Agreement with Assisted Dying

The distribution of physician responses about the use of assisted dying in advanced dementia was as follows: completely agree, 4.7% (*n* = 3/64); somewhat agree, 15.6% (*n* = 10/64); somewhat disagree, 26.6% (*n* = 17/64); completely disagree, 50.0% (*n* = 32/64); and do not know, 3.1% (*n* = 2/64). The distribution among the surrogates was: completely agree, 20.2% (*n* = 34/168); somewhat agree, 26.8% (*n* = 45/168); somewhat disagree, 23.2% (*n* = 39/168); completely disagree, 22.6% (*n* = 38/168); and do not know, 7.1% (*n* = 12/168).

In the unadjusted analyses, participant variables associated with agreement with assisted dying at *p* < 0.10 were: age >55 years; any prior major treatment decision in dementia; and being a surrogate (vs. a physician) (Table 2). After multivariable adjustment, only being a surrogate (vs. a physician) remained significantly associated with a higher likelihood of agreeing with the use of assisted dying (AOR, 3.87; 95% CI: 1.94, 7.69). When analyzing surrogate subgroups, agreement was significantly more likely among relatives than among proxies (34.6 vs. 16.0%; AOR, 2.00; 95% CI: 1.04, 3.83) (Appendix, Table 1).

#### Agreement with CDS

The distribution of physician responses about the use of CDS in advanced dementia was as follows: completely agree, 20.3% (*n* = 13/64); somewhat agree, 31.3% (*n* = 20/64); somewhat disagree, 31.3% (*n* = 20/64); completely disagree, 6.3% (*n* = 4/64); and do not know, 10.9% (*n* = 7/64). The distribution among the surrogates was: completely agree, 12.6% (*n* = 21/167); somewhat agree, 29.3% (*n* = 49/167); somewhat disagree, 28.7% (*n* = 48/167); completely disagree, 18.6% (*n* = 31/167); and do not know, 10.8% (*n* = 18/167).

The only covariate associated with a greater likelihood of supporting the use of CDS at *p* ≤ 0.10 was “no religion” (vs. “any”) (Table 3). After adjusting for religion, being a surrogate (vs. a physician) remained not significantly associated with agreement with the use of CDS (AOR, 0.69; 95% CI: 0.36, 1.29). When analyzing surrogate subgroups, agreement was significantly more likely among relatives than among proxies (34.9 vs. 12.1%; AOR, 2.82; 95% CI: 1.41, 5.64) (Appendix, Table 2).

#### Discussion

In this report, a minority of the physicians (20%) and about half of the surrogates (47%) supported the use of assisted dying for patients with advanced dementia. Sur-

**Table 3.** Association between decision-maker type and agreement with the use of continuous deep sedation in advanced dementia

	Decision-makers with the characteristic ( <i>n</i> = 206), <i>n</i> (%)	Decision-makers agreeing with continuous deep sedation ( <i>n</i> = 103), <i>n</i> (%)		Odds ratio <sup>a</sup> for agreement with continuous deep sedation (95% CI)	
		characteristic present	characteristic absent	unadjusted	adjusted
<i>Characteristic</i>					
Surrogate (vs. physician)	149 (72.3)	70 (34.0)	33 (16.0)	0.64 (0.35, 1.19)	0.69 (0.36, 1.29) <sup>e</sup>
<i>Covariates</i>					
Age >55 years <sup>b</sup>	101 (49.3)	55 (26.8)	48 (23.4)	1.39 (0.81, 2.42)	
Female <sup>b</sup>	128 (62.4)	64 (31.2)	39 (19.0)	0.97 (0.55, 1.71)	
No religion (vs. any) <sup>b</sup>	41 (20.9)	27 (13.8)	74 (37.8)	2.11 (1.03, 4.33) <sup>d</sup>	2.19 (1.06, 4.51)
Any prior major treatment decision in dementia <sup>b, c</sup>	88 (43.1)	47 (23.0)	55 (27.0)	1.27 (0.73, 2.22)	

Decision-makers: 50.0% (*n* = 103/206) agreed with the use of continuous deep sedation in advanced dementia. <sup>a</sup> Logistic regression was used in all analyses, and unadjusted and adjusted odds ratios were computed. <sup>b</sup> The total number of missing values was: age, *n* = 1; female, *n* = 1; no religion, *n* = 10 (missing values, *n* = 2; refused, *n* = 8); and any prior major treatment decision, *n* = 2. <sup>c</sup> Decision-makers reported whether they had or had not previously made any major decision about the use of antibiotics and/or artificial hydration for a person with advanced dementia. <sup>d</sup> The only variable that was significant at *p* < 0.10 in the bivariable analyses and entered into the multivariable model. <sup>e</sup> After adjusting for religion, the association between being a surrogate and agreement with the use of continuous deep sedation remained not significant.

rogates were significantly more likely to agree with the use of this practice than physicians. About half of the physicians (52%) and a slightly lower proportion of the surrogates (42%) agreed with the use of CDS for these patients, which was not a significant difference between the groups.

This study confirms and extends the limited existing research on the perceptions of physicians and surrogates about assisted dying in advanced dementia [11–15]. The use of assisted dying has increased in countries where it is legal (The Netherlands and Belgium) over the last decade, but much less frequently for patients with dementia than for those with terminal illnesses that do not impact decision-making abilities [6, 10, 22]. Prior research has shown that most physicians are opposed to the use of this practice in dementia [12–15]. Irrespective of the presence of an advance directive, physicians are reluctant to perform physician-assisted suicide for patients lacking decision-making capacity [12]. A Dutch study on 1,456 physicians found that physicians were more willing to perform assisted dying for cancer patients with intact cognition (85%) than for advanced dementia patients who had requested euthanasia in an advance directive prepared when they were still capable of making medical decisions (33%) [14]. Similar proportions were found in a recent Canadian study on 136 physicians [15]. Notably,

this study also showed that agreement increased to 71% when the hypothetical scenario specified that the dementia patients were in their last days of life. One chief concern is that preferences change over time [23], and that patients who imagine a future state with advanced dementia as one not worth living, once in that state, may appear to still retain a desire to live. Although surrogates may share this concern, their more favorable view of the use of assisted dying may be driven by a relatively greater aversion to their loved one experiencing the poor quality of life, suffering, and indignities of advanced dementia [11, 13]. The greater likelihood of surrogates agreeing to assistance in dying is due to the fact that their participation, unlike physicians, is not required to complete the act.

Our findings build on the very limited data on the use of CDS in advanced dementia [3, 15, 20], and they reveal that there is no consensus among either physicians or surrogates about the appropriateness of using CDS in this population. This finding corroborates qualitative research showing that both groups of key decision-makers have mixed feelings about the use of this practice among terminally ill patients [24, 25]. To date, CDS has predominantly been used and studied in advanced cancer, a condition where decision-making capacity remains intact and the dying process is most commonly

accompanied by intractable physical pain and suffering [16, 19]. In contrast to these patients, advanced dementia patients cannot participate in decision-making or report the source of their discomfort due to their serious cognitive impairments [5]. Therefore, it may be challenging for physicians to assess the intensity of a patient's suffering, making it difficult to justify the use of CDS in advanced dementia. Furthermore, pain and agitation in advanced dementia are often caused by other medical complications, such as infections, and may be effectively controlled with standard palliative medications [3, 4].

This study has several limitations that merit discussion. First, our participation rate was low, and thus our findings cannot be generalized to eligible nonparticipants. Second, generalizability is also limited to the Swiss German region of Switzerland and to hypothetical situations. The perceptions about end-of-life practices may vary in other regions of Switzerland and in real-life situations. In addition, it cannot be ruled out that physicians unaffiliated with associations promoting palliative care may hold different views on end-of-life practices. Third, the questions may not have been detailed enough to detect nuances in participants' perceptions [26]. It is likely that participants' opinions would have been different if they had been given more information, such as a statement indicating that the patient had made a written request for assisted dying before losing decision-making capacity. Likewise, providing participants with background information and definitions of different end-of-life practices such as physician-assisted suicide and euthanasia in the case of incompetent patients would likely have altered the responses. Lastly, the statistical power may have been insufficient to detect significant differences in secondary outcomes, notably differences in perceptions about CDS. Future work should replicate these findings in a clinical cluster-randomized trial.

This study expands upon the limited existing literature on the perceptions of physicians and surrogates about the use of assisted dying and CDS for patients with advanced dementia. Physicians were more opposed to the use of assisted dying than were the surrogates, and about half of the participants in both groups perceived CDS as an appropriate option in advanced dementia. In general, there is a clear need to improve end-of-life care in this patient population. However, due to the practical, ethical, and legal issues associated with performing assisted dying and CDS for patients who lack decision-making capacity, it remains unclear whether these prac-

tices would help accomplish this goal. Early goals of care discussions can promote decisions that align with the patient's preferences and the use of standard palliative medications [27, 28].

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## Statement of Ethics

The ethics commission of the canton of Zurich approved the study's conduct (KEK-ZH-No. 2015-0626). All participants provided written informed consent. The authors have no ethical conflicts to disclose.

## Disclosure Statement

The authors have no conflicts of interest to declare.

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## Author Contributions

F.R. and A.J.L. had full access to all data in the study and take responsibility for the integrity of the data and the accuracy of the data analyses. Study concept and design: A.J.L., N.T., S.E., M.M., and F.R.; acquisition of data: A.J.L., S.M.C., S.L.M., N.T., S.E., M.M., and F.R.; analyses and interpretation of data: A.J.L., S.M.C., S.L.M., N.T., S.E., M.M., and F.R.; drafting of manuscript: A.J.L., S.M.C., S.L.M., and F.R.; critical revision of manuscript for important intellectual content: A.J.L., S.M.C., S.L.M., N.T., S.E., M.M., and F.R.; statistical analyses: A.J.L., S.M.C., S.L.M., N.T., M.M., and F.R.; administrative, technical, or material support: A.J.L., S.E., and F.R.; and study supervision: A.J.L., N.T., S.E., M.M., and F.R.

## Appendix

**Table 1.** Association between being a relative versus a proxy and agreement with the use of assisted dying in advanced dementia

	Surrogates with the characteristic ( <i>n</i> = 156), <i>n</i> (%)	Surrogates agreeing with assisted dying ( <i>n</i> = 79), <i>n</i> (%)		Odds ratio <sup>a</sup> for agreement with assisted dying (95% CI) adjusted <sup>b</sup>
		characteristic present	characteristic absent	
<i>Characteristic</i>				
Relative (vs. proxy)	94 (60.3)	54 (34.6)	25 (16.0)	2.00 (1.04, 3.83)

Surrogates: 50.6% (*n* = 79/156) agreed with the use of assisted dying in advanced dementia. <sup>a</sup> Logistic regression was used in all analyses, and unadjusted and adjusted odds ratios were computed. <sup>b</sup> After accounting for age, gender, religion, and prior decisions about antibiotics/artificial hydration use, no variables were significant at *p* < 0.10 in the bivariable analyses, except for the association between being a relative versus proxy and agreement with the use of assisted dying in advanced dementia.

**Table 2.** Association between being a relative versus a proxy and agreement with the use of continuous deep sedation in advanced dementia

	Surrogates with the characteristic ( <i>n</i> = 149), <i>n</i> (%)	Surrogates agreeing with continuous deep sedation ( <i>n</i> = 70), <i>n</i> (%)		Odds ratio <sup>a</sup> for agreement with continuous deep sedation (95% CI) adjusted <sup>b</sup>
		characteristic present	characteristic absent	
<i>Characteristic</i>				
Relative (vs. proxy)	92 (61.7)	52 (34.9)	18 (12.1)	2.82 (1.41, 5.64)

Surrogates: 47.0% (*n* = 70/149) agreed with the use of continuous deep sedation in advanced dementia. <sup>a</sup> Logistic regression was used in all analyses, and unadjusted and adjusted odds ratios were computed. <sup>b</sup> After accounting for age, gender, religion, and prior decisions about antibiotics/artificial hydration use, no variables were significant at *p* < 0.10 in the bivariable analyses, except for the association between being a relative versus proxy and agreement with the use of continuous deep sedation in advanced dementia.

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